Research Article
Artigo de Pesquisa
Artículo de Investigación

DOI: https://doi.org/10.12957/reuerj.2024.80769

Prevalence of painful symptoms in women with endometriosis in a capital of Northeastern Brazil

Prevalência dos sintomas dolorosos em mulheres com endometriose em uma capital o nordeste brasileiro

Prevalencia de síntomas de dolor en mujeres con endometriosis en una capital del noreste de Brasil

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ABSTRACT

Objective: to analyze the prevalence of painful symptoms in women with endometriosis in a capital of northeastern Brazil. **Method:** a cross-sectional, descriptive survey study with a quantitative approach was conducted with 107 women receiving care at two specialized endometriosis centers. After approval by the research ethics committee, data collection took place from January to August 2023, using a form containing sociodemographic data and the Endopain 4D instrument. Data were subjected to descriptive statistical analysis and the application of Chi-square and Fisher's exact tests. **Results**: the majority of women were aged between 40 and 44 years, married, brown, with higher education, and a family income exceeding one minimum wage. A statistically significant association was observed between high levels of pain and symptoms related to dysmenorrhea, dyspareunia, dyschezia, and bowel changes. **Conclusion:** pain in women with endometriosis is associated with various aspects of dysmenorrhea, dyspareunia, and dyschezia.

Descriptors: Women's Health; Endometriosis; Pain; Pain Measurement.

RESUMO

Objetivo: analisar a prevalência dos sintomas dolorosos em mulheres com endometriose em uma capital do nordeste brasileiro. **Método:** estudo transversal e descritivo do tipo *Survey,* com abordagem quantitativa, realizado com 107 mulheres acompanhadas em dois centros especializados em endometriose. Após aprovação do comitê de ética em pesquisa, a coleta dos dados aconteceu de janeiro a agosto de 2023, utilizando um formulário contendo dados sociodemográficos e o instrumento *Endopain* 4D. Os dados foram submetidos às análises estatísticas descritiva e com aplicação dos Testes qui-quadrado e exato de Fisher. **Resultados**: a maioria das mulheres possui entre 40 e 44 anos, são casadas, pardas, com ensino superior e renda familiar de mais de um salários-mínimos. Observou-se uma associação estatisticamente significativa entre altos níveis de dor e sintomas relacionados a dismenorreia, dispareunia, disquesia e alterações intestinais. **Conclusão:** a dor em mulheres com endometriose associa-se a diversos aspectos da dismenorreia, da dispareunia e da disquesia.

Descritores: Saúde da Mulher; Endometriose; Dor; Avaliação da Dor.

RESUMEN

Objetivo: analizar la prevalencia de síntomas de dolor en mujeres con endometriosis en una capital del noreste de Brasil. **Método:** estudio transversal, descriptivo tipo *Survey*, con enfoque cuantitativo, realizado con 107 mujeres que se les hace seguimiento en dos centros especializados en endometriosis. Se obtuvo la aprobación del comité de ética en investigación y, posteriormente, se realizó la recolección de datos de enero a agosto de 2023, mediante un formulario que contiene datos sociodemográficos y el instrumento *Endopain* 4D. Los datos fueron sometidos a análisis estadístico descriptivo por medio de las pruebas de chi-cuadrado y exacta de Fisher. **Resultados:** la mayoría de las mujeres tienen entre 40 y 44 años, están casadas, son mulatas, tienen educación superior y un ingreso familiar superior a un salario mínimo. Se observó una asociación estadísticamente significativa entre niveles elevados de dolor y síntomas relacionados con dismenorrea, dispareunia, disquesia y problemas intestinales. **Conclusión:** el dolor en mujeres con endometriosis se asocia con diferentes aspectos de la dismenorrea, dispareunia y disquecia

Descriptores: Salud de la Mujer; Endometriosis; Dolor; Dimensión del Dolor.

INTRODUCTION

Endometriosis is a chronic and debilitating disease characterized by the presence of endometrial tissue outside the uterine cavity[1,2]. In this clinical condition, women may experience painful symptoms and infertility, although some may remain asymptomatic[3].

The prevalence of the disease is not clearly established. However, studies indicate that endometriosis affects 10 to 15% of women of reproductive age and is observed in 50–80% of women with pelvic pain and up to 50% of women with infertility, with more than 176 million women affected worldwide[2,4]. Despite this high prevalence, recognition of the disease remains inadequate, with a diagnostic delay ranging from 4 to 11 years, and 65% of women initially misdiagnosed[2].

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Editor in chief: Cristiane Helena Gallasch; Associate Editor: Juliana Amaral Prata

Received: Dec 14th 2023 – Accepted: Oct 8th 2024

Research Article
Artigo de Pesquisa
Artículo de Investigación

DOI: https://doi.org/10.12957/reuerj.2024.80769

Pain is one of the most predominant clinical features of the disease, manifesting as dysmenorrhea, chronic pelvic pain or acyclic pain, deep dyspareunia, infertility, and cyclic bowel changes (abdominal bloating, blood in stools, constipation, dyschezia, and anal pain) and urinary symptoms (dysuria, hematuria, increased urinary frequency, and urgency) during menstruation. It is important to note that these symptoms may or may not be present and can be associated with other gynecological conditions, such as leiomyomas and adenomyosis, or non-gynecological conditions, such as interstitial cystitis and irritable bowel syndrome[1,5].

Over time, active and progressive disease contributes to increased pain, with the potential for the development of other processes, such as peritoneal fluid inflammation, neurogenic inflammation, neuroangiogenesis, and peripheral and central pain sensitization mechanisms[6]. Regardless of the clinical presentation, symptoms can have significant personal effects, causing substantial social, physiological, psychological, and economic discomfort for affected women, their partners, and families, making the condition as complex as the disease itself. Additionally, factors such as psychological and physical stress, hormonal status, and various coping mechanisms are known to influence pain perception[7].

Given this issue, the following question emerged: What is the prevalence of pain in women with endometriosis in a capital of northeastern Brazil? To address this question, the study aimed to analyze the prevalence of painful symptoms in women with endometriosis in a capital of northeastern Brazil.

METHOD

This is a cross-sectional, descriptive survey study with a quantitative approach, conducted from January to August 2023 at two specialized endometriosis referral centers in the state of Alagoas, Brazil. One center is part of the private healthcare network, offering services both privately and through insurance, with a multidisciplinary and multiprofessional team specialized in the treatment of deep endometriosis. This team includes gynecologists, colorectal surgeons, urologists, specialized radiologists, nurses, nutritionists, and social workers. The other institution is a teaching hospital offering various specialties, multiprofessional teams, diagnostic and surgical centers, and is affiliated with the Unified Health System (SUS).

The study population consisted of 107 women diagnosed with endometriosis who were treated during the data collection period, of which 94 were from the private institution and 13 from the public institution. The sampling method was convenience sampling, a non-probabilistic and non-random technique.

Inclusion criteria included having a diagnosis of endometriosis, regardless of duration, confirmed by laparoscopy, magnetic resonance imaging, and/or mapping ultrasound. Women were excluded if they were unable to participate due to emotional issues, cognitive impairments (diagnosed with Alzheimer's or other neurodegenerative disorders), or severe verbal communication disabilities at the time of data collection.

After receiving approval from the research ethics committee, recruitment began in the waiting rooms of the institutions. Once the inclusion criteria were verified, participants were provided with the Free and Informed Consent Form or the Free and Informed Assent Form, with clarifications about the study.

Upon agreement to participate, a structured form containing ten questions on sociodemographic data (age group, race/color, marital status, education, and family income) was administered, followed by the validated Endopain 4D questionnaire[8].

Endopain 4D is a validated questionnaire in some countries, and in Brazil, it is in the validation phase. It is used to measure painful symptoms of endometriosis based on women's verbal descriptions. The form has content validity, reflecting the subjective experiences of women with endometriosis pain, providing a solid foundation for developing an efficient, patient-centered instrument to measure these pain symptoms[8].

Endopain 4D consists of 21 items divided into four sections describing pain: spontaneous pelvic pain and dysmenorrhea (questions 1 to 10), dyspareunia (questions 11 to 13), intestinal pain symptoms (questions 14 to 16), and other symptoms (questions 17 to 21). The score is generated based on the extent of the symptom for the "yes" response, with scores ranging from "0": no pain to "10": worst imaginable pain[8].

Before data collection, the questionnaire was tested to ensure adaptations related to subjective pain questions and the diagnosis of endometriosis, respecting each woman's described context. The test was satisfactory, and no adjustments to the form were necessary. All approached women agreed to participate in the study, with no refusals or losses during the data collection period.

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After data collection, the information obtained from the questionnaires was stored in Microsoft Excel 2010 spreadsheets. Descriptive analysis of the sample was then performed, calculating absolute (n) and relative (f) frequencies for dependent and independent variables such as age group, per capita family income, education, marital status, self-reported race/color, pain in women with endometriosis, and the type, frequency, and location of pain.

Inferential statistical analysis was conducted using the JAMOVI program (Version 2.4)9,10, applying the Shapiro-Wilk test. For comparisons between the two groups, the Chi-square test and Fisher's exact test were used to assess pain level, location, type, and frequency. The study adopted a 95% confidence interval and a significance level of 5% ($p<0.05$). The data were presented in tables and discussed based on the literature.

RESULTS

A total of 107 questionnaires were administered, of which 12.1% (n=13) were completed at the endometriosis outpatient clinic of the public service, while 87.8% (n=94) were completed at the private institution. The participants' profile is presented in Table 1.

Table 1: Sociodemographic profile of women living with endometriosis in a state in the Northeastern region of Brazil, Maceió, AL, Brazil, 2023.

Variable		n	f(%)
Age group (years old)	15-19	5	4.7
	20-24	6	5.6
	25-29	13	12.1
	30-34	17	15.9
	35-39	27	25.2
	40-44	28	26.2
	>45	11	10.3
Race	White	34	31.8
	Brown	54	50.5
	Black	16	15.0
	Asian	3	2.8
	Indigenous	-	-
Marital status	Single	37	34.6
	Married	59	55.1
	Divorced	6	5.6
	Stable union	3	2.8
	Widowed	2	1.9
Schooling	Fundamental 1	2	1.9
	Fundamental 2	5	4.7
	Complete High School	40	37.4
	Education	42	39.3
	Graduate Studies	18	16.8
Family income	<1 minimum wage	12	11.2
	=1 - 3 minimum wages	32	29.9
	=3 – 5 minimum wages	31	29.0
	≥ 5 minimum wages	32	29.9

Observing the sociodemographic profile of the study participants, the majority were aged between 40-44 years (n=28; 26.2%), married (n=59; 50.5%), brown (n=54; 50.5%), had higher education (n=42; 39.3%), and a family income between one to three and above five minimum wages (n=29; 29.9%).

Table 2 describes the first part related to the prevalence of painful symptoms reported by women living with endometriosis, based on questions regarding pain experienced during the menstrual period.

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Table 2: Prevalence of painful symptoms reported by women living with endometriosis in a state in the northeastern region of Brazil, Maceió, AL, Brasil, 2023.

Variable	No n(%)	Yes n(%)
Severe and violent pain in the lower abdomen during your period?	09 (8.40%)	98 (91.6%)
Severe and violent pain in the lower abdomen between periods?	31 (29.0%)	76 (71.0%)
Is the pain very intense, violent, impossible to ignore, and unbearable?	25 (23.4%)	82 (76.6%)
Has the pain worsened over the years?	35 (32.7%)	72 (67.3%)
Does the pain start a few days before your period and/or continue for a few days after?	27 (25.2%)	80 (74.8%)
Does the pain come and go suddenly, like stabbing pain?	24 (22.4%)	83 (77.6%)
Does the pain spread to your lower back?	25 (23.4%)	82 (76.6%)
Does the pain spread to your legs and hips?	31 (29.0%)	76 (71.0%)
Does the pain become disabling for daily activities?	26 (24.3%)	81 (75.7%)
Does the pain prevent you from standing, walking, or moving?	27 (25.2%)	80 (74.8%)
Severe, sharp, and deep internal pain during sexual intercourse?	42 (39.3%)	65 (60.7%)
Pain felt in certain positions during sexual intercourse?	53 (49.5%)	54 (50.5%)
Pain that disrupts, prevents, or interrupts sexual intercourse?	53 (49.5%)	54 (50.5%)
Pain during bowel movements, especially during your period?	37 (34.6%)	70 (65.4%)
Spasms, cramps, or intestinal pain before a bowel movement, particularly during your period?	21 (19.6%)	86 (80.4%)
Diarrhea and/or constipation, especially during your period?	17 (15.9%)	90 (84.1%)
Bladder pain when you need to urinate or when holding it, especially during your period?	56 (52.3%)	51 (47.7%)
Sciatic pain, particularly during your period?	52 (48.6%)	55 (51.4%)
Right shoulder pain or pain under the right rib cage, particularly during your period?	72 (67.3%)	35 (32.7%)
Difficulty getting pregnant or conceiving despite trying for several months or years?	31 (29.0%)	48 (44.9%)

Regarding the second section on dyspareunia, just over half of the participants reported experiencing severe, sharp, and deep internal pain during sexual intercourse (n=65; 60.7%), pain in certain positions during intercourse (n=54; 50.5%), and pain that disrupts or interrupts sexual activity (n=54; 50.5%). In the third section, related to intestinal pain symptoms, the majority reported pain during bowel movements, particularly during menstruation (n=70; 65.4%), spasms, cramps, or intestinal pain before a bowel movement (n=86; 80.4%), and diarrhea and/or constipation during menstruation (n=90; 84.1%).

In the final section on other symptoms, a minority reported bladder pain when needing to urinate or when holding it during menstruation (n=51; 47.7%), right shoulder pain during menstruation (n=35; 32.7%), and difficulties conceiving (n=48; 44.9%). However, slightly more than half experienced sciatic pain during menstruation (n=55; 51.4%).

Data analysis also revealed a statistically significant association between high pain levels and symptoms related to dysmenorrhea in the first part of the questionnaire, namely: severe and violent lower abdominal pain during menstruation (p=0.002), intense, violent, and unbearable pain (p<0.001), worsening pain over the years (p<0.001), pain starting a few days before period and/or continuing for a few days after (p<0.001), pain spreading to the lower back (p<0.001), pain becoming disabling for daily activities (p<0.001), and pain preventing standing, walking, or moving (p<0.001).

In the second section of the questionnaire, there was a significant association between dyspareunia symptoms and pain felt in certain positions during intercourse (p=0.002) and pain that disrupts, prevents, or interrupts sexual activity (p=0.002). In the third section on dyschezia, all symptoms showed significant associations, including pain during bowel movements, especially during menstruation (p<0.001), spasms, cramps, or intestinal pain before a bowel movement, particularly during menstruation (p<0.001), and diarrhea and/or constipation, especially during menstruation (p<0.001). However, in the final section on other symptoms, no significant associations were found.

DISCUSSION

The results showed that most women living with endometriosis are aged between 40 and 44 years, are brown, married, have completed higher education, and have a family income above one minimum wage. In this context, endometriosis generally affects women of reproductive age, with an average age of 36 years[11,12].

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Although the results indicate this age range, many women with endometriosis experience symptoms before the age of 20. However, endometriosis is a disease with a long delay between symptom onset and diagnosis, and being progressive, it leads to increased pain levels in older age groups due to the lack of early detection and diagnosis[5,6].

Regarding marital status, women with endometriosis often receive a diagnosis after marriage, as they seek healthcare services due to complaints of infertility and/or symptoms affecting their sexual life[12,13], consistent with the findings of this study.

As for the race/color variable, these results align with data from the Brazilian Institute of Geography and Statistics (IBGE)[14], which shows that most of the Brazilian population self-identifies as brown. Regarding family income, a study[15] found that the average individual income was four minimum wages, while married women had a family income of around ten minimum wages, which does not align with this study. Moreover, women with higher incomes have access to more effective medications and medical treatments, often resulting in a more favorable prognosis and reduced pain levels[13].

Globally, literature indicates that, regardless of the healthcare system, the delay between symptom onset and endometriosis diagnosis is between six and ten years. This delay has significant consequences not only for the woman (infertility, reduced ovarian reserve, major complications such as bowel obstruction, kidney damage, sexual dysfunction, relationship issues, fatigue, depression, central sensitization with brain and/or peripheral consequences, and patient-doctor relationship deterioration) but also for the couple and society (work productivity loss and a substantial economic burden)[16].

Thus, it is evident that endometriosis significantly impacts women's quality of life, affecting physical, psychological, social, familial, sexual, educational, and professional aspects, reducing quality of life and harming marital/sexual relationships, especially considering the chronic nature of the disease and its association with infertility and dyspareunia[5].

Regarding the epidemiology of endometriosis, most women report dysmenorrhea, often associated with other symptoms such as dyspareunia or chronic pelvic pain, consistent with this study[17]. Additionally, women with endometriosis report intense pain and other debilitating consequences that compromise their quality of life[18].

Dysmenorrhea is typically one of the most prevalent symptoms and can be considered the best marker of the disease, along with physical exam findings and complementary tests that may indicate the presence of the pathology. However, this symptom is still often neglected and associated with other conditions, making timely diagnosis and treatment initiation difficult[19].

Another important and prevalent symptom is dyspareunia, defined as pain during or after sexual intercourse. It is classified into two types: superficial, with pain around the vaginal introitus, and deep, with pain during deep penetration. This symptom significantly impacts sexual, emotional, and psychological health, causing various harms to marital life and quality of life. In this context, a study showed that most participants reported at least one complaint regarding desire, satisfaction, frequency of intercourse, or pain, with dyspareunia being the most prevalent symptom. Additionally, some women reported being able to manage painful symptoms by reducing or suppressing their influence on affected aspects, allowing them to enjoy sexual relations with their partners[20].

Despite reports from women with endometriosis indicating the possibility of living with dyspareunia and maintaining relationships, a quality-of-life study showed that most women avoid sexual intercourse due to dyspareunia[21]. This recurring symptom creates a pathogenic mechanism that generates negative experiences, significantly impacting sexuality, quality of life, personal well-being, self-care, self-esteem, and psychological well-being, not only for the women but also for their partners[22]. This finding was also significant in the evaluation conducted using the questionnaire.

Additionally, endometriosis can cause gastrointestinal symptoms due to the depth of tissue infiltration and nerve involvement, particularly somatic and autonomic nerves, leading to dyschezia, hematochezia, diarrhea, constipation, tenesmus, and rectal bleeding during menstruation, consistent with this study[23.]

In the clinical evaluation of women with endometriosis, the urinary tract may also be involved, exacerbating pelvic pain and symptoms such as dysuria and increased urinary frequency, consistent with this study's findings[24].

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Another symptom reported in the results was sciatic pain in women with endometriosis. This occurs due to endometriotic lesions affecting the sciatic nerve, increasing the risk of lumbosacral neuropathy, which irritates the dermatomes that make up this plexus, causing pain and/or gait disturbances. Although described as rare, it can occur in some cases[25,26]. This symptom was observed in many women in this study, but no significant association was found.

Shoulder pain, another uncommon symptom in women with endometriosis, is associated with lesions in the thoracic cavity, particularly affecting the diaphragm, and is referred to as Thoracic Endometriosis Syndrome. This condition produces a series of clinical and radiological manifestations, including catamenial pneumothorax, catamenial hemothorax, catamenial hemoptysis, and pulmonary nodules[27,28]. However, despite being described in the literature, it was not reported in this study.

Despite limited advances in early diagnosis of endometriosis, efforts toward its detection and related studies have strengthened care for women living with undiagnosed endometriosis. Endometriosis affects millions of women worldwide, directly impacting their quality of life and relationships, bringing negative effects on their well-being and that of those around them[29].

Describing the findings of this study, using subjective data reported by women through the ENDOPAIN 4D, may offer new perspectives for evaluating pain responses to treatments, enabling routine follow-up to anticipate and accelerate endometriosis investigation, as well as monitor prognosis and quality of life changes with treatment[20].

A endometriose, por ser uma doença ainda de diagnóstico tardio, os sintomas referidos pelas mulheres são grandes achados para auxiliar no processo de diagnósticos rápido e assim melhorar a qualidade de vida delas o mais brevemente possível e os profissionais de saúde e dentre eles o da enfermagem, por estarem envolvidos com os cuidados referentes a saúde da mulher, podem propor protocolos que trabalhem com estratégia para o avanço da descoberta precoce e das adaptações referentes ao conviver com o diagnóstico[20].

Study limitations

Regarding the limitation encountered, it is important to highlight the subjectivity reported by women living with endometriosis in relation to pain and their process of feeling and describing it, as well as the cross-cultural context that may introduce bias in the responses related to the symptoms they reported. Additionally, no causal relationships are established.

CONCLUSION

Based on the study results, it was observed that among the women studied, symptoms related to dysmenorrhea, dyspareunia, dyschezia, gastrointestinal changes, and sciatic pain were associated with high levels of reported pain.

It is important to emphasize that care for endometriosis should go beyond conventional and/or medicinal treatments, focusing on managing lifestyle habits to reduce painful symptoms and improve quality of life. In this context, healthcare professionals, especially nurses, need to stay informed and attentive to the painful symptoms reported and the forms of care for those living with endometriosis, considering that caregiving is the essence of nursing practice.

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Conceptualization, H.G.S.O. and A.A.P.S.; methodology, H.G.S.O., K.F.F. and A.A.P.S.; validation, H.G.S.O., K.F.F. and A.A.P.S.; formal analysis, H.G.S.O., K.F.F. and A.A.P.S.; investigation, H.G.S.O., J.S.B.S., N.V.S.T. and G.V.O.M.; resources, A.A.P.S.; data curation, H.G.S.O. and A.A.P.S.; manuscript writing, H.G.S.O., J.S.B.S., N.V.S.T., G.V.O.M., K.F.F. and A.A.P.S.; writing – review and editing, H.G.S.O., J.S.B.S., N.V.S.T., G.V.O.M., K.F.F. and A.A.P.S.; visualization, K.F.F. and A.A.P.S., supervision, A.A.P.S.; project administration, K.F.F. and A.A.P.S. All authors read and agreed with the published version of the manuscript.